



National Institute of
Neurological Disorders
and Stroke



NANDSC ME/CFS Research Roadmap Working Group

Background

In 2019, the National Advisory Neurological Disorders and Stroke (NANDSC) Council Working Group for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) presented the [Report of the NANDSC Council Working Group for ME/CFS Research](#) (pdf, 669 KB). In 2022, as part of the strategic planning process outlined in the report, NINDS announced the development of a Research Roadmap for ME/CFS, which identified research priorities to move the field toward translational studies and clinical trials.

The roadmap was informed by a new working group, which will include ME/CFS basic and clinical experts from the research community, leaders of ME/CFS non-profit advocacy and research organizations, as well as people with lived experience (*i.e.*, individuals with ME/CFS, those with a family history of ME/CFS, caregivers/care partners, and/or patient advocates). The working group met regularly in 2023 and 2024 to discuss and develop a Research Roadmap for ME/CFS.

Members of the [Trans-NIH ME/CFS Working Group](#) and staff from the [NINDS Office of Science Policy and Planning](#) and the [NINDS Office of Neuroscience Communications and Engagement](#) coordinated the activities of the ME/CFS Research Roadmap Working Group. The roadmap was presented at the [NANDSC Council meeting](#) on May 15, 2024. A recording of the Council meeting is on [NIH videocast](#).



Report of the ME/CFS Research Roadmap Working Group of Council

The research roadmap is now available!

[Read the Full Report](#)

(pdf, 3436 KB)

Charge of the Committee

The new NANDSC Council Working Group will develop a research roadmap to provide scientific guidance to the NANDSC Council on how best to advance research on ME/CFS. Consistent with the charge, the working group:

- Assessed current ME/CFS research activities and identified opportunities and gaps in ME/CFS research to identify targets for the development of treatments.

Process, Deliverables, and Timeframe

This working group of the NANDSC Council:

- Held a series of [virtual webinars](#) to assess current efforts and identify opportunities for research.
- Sought input broadly from all relevant communities, including researchers, clinicians, non-profit advocacy organizations, people with lived experience, and other federal agencies.
- Presented the draft roadmap to the community at a public webinar.
- Presented the final roadmap to the full NANDSC Council at the [May 2024 meeting](#).
- Utilized information, recommendations, and feedback from:
 - Institute of Medicine Report [Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness](#)
 - [Report of the NANDSC Council Working Group for ME/CFS Research](#) (pdf, 669 KB)
 - ME/CFS community

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Working Group Members

Co-chairs

Lucinda (Cindy) Bateman, M.D.

Founder and Medical Director

Bateman Horne Center

Salt Lake City, UT

Maureen Hanson, Ph.D.

Liberty Hyde Bailey Professor

Department of Molecular Biology and Genetics

Cornell University

Ithaca, NY

Members

Oved Amitay

Chief Executive Officer

Solve ME/CFS Initiative

Glendale, CA

Simon Carding, Ph.D.

Professor

Norwich Medical School, University of East Anglia

Programme Leader, Quadrum Institute Bioscience

Norwich Research Park

Norwich, UK

H. Craig Heller, Ph.D.

Professor

Department of Biology

Stanford University

Stanford, CA

David Holcomb

San Diego, CA

Leonard Jason, Ph.D.

Director of Center for Community Research and Professor

DePaul University

Chicago, IL

Cort Johnson

Health Rising

Henderson, NV

Laurie Jones

Executive Director

#MEAction

Santa Monica, CA

Nancy Klimas, M.D.

Director, Institute for Neuro-Immune Medicine

Director, Clinical Immunology Research, Miami VAMC GRECC

Professor and Chair, Department of Clinical Immunology College of Osteopathic Medicine

Nova Southeastern University

Ft. Lauderdale, FL

Anthony L. (Tony) Komaroff, M.D.

Simcox-Clifford-Higby Distinguished Professor of Medicine

Harvard Medical School

Senior Physician
Brigham and Women's Hospital
Boston, MA

Gudrun Lange, Ph.D.
Independent Practitioner
Consultant
Clinical Neuropsychologist
Pain & Fatigue Study Center
Icahn School of Medicine at Mt. Sinai
New York, NY

Susan Levine, M.D.
New York, NY

W. Ian Lipkin, M.D.
John Snow Professor of Epidemiology
Professor of Pathology and Cell Biology
Director, Center for Infection and Immunity
Columbia University
New York, NY

Alain Moreau, Ph.D.
Director, Interdisciplinary Canadian Collaborative Myalgic Encephalomyelitis Research Network
Full Professor, Department of Stomatology, Faculty of Dentistry
Department of Biochemistry and Molecular Medicine, Faculty of Medicine at Université de Montréal
Scientific Director, Open Medicine Foundation Collaborative Research Center at CHU Sainte-Justine/Université de Montréal
Montreal, Quebec, Canada

Benjamin Natelson, M.D.
Professor
Pain & Fatigue Study Center
Department of Neurology
Icahn School of Medicine at Mount Sinai
New York, NY

Beth Pollack
Research Scientist
Director, Project Connect at MIT
Tal Research Group
Department of Biological Engineering
Massachusetts Institute of Technology
Cambridge, MA

Chris Ponting, Ph.D.
Professor
The University of Edinburgh
MRC Human Genetics Unit
Institute of Genetics and Cancer
Edinburgh, UK

Richard Simpson
Trustee, Invest in ME Research
Eastleigh, Hampshire, UK
Chair of European ME Alliance

David Systrom, M.D.
Director, Advanced Cardiopulmonary Exercise Testing Program
Assistant Professor of Medicine
Brigham and Women's Hospital, Harvard Medical School
Boston, MA

Linda Tannenbaum
Founder & CEO/President
Open Medicine Foundation

Agoura Hills, CA

Elizabeth (Beth) Unger, M.D., Ph.D.

Chief of the Chronic Viral Disease Branch (CVDB)
Division of High-Consequence Pathogens and Pathology
National Center for Emerging and Zoonotic Infectious Diseases
Center for Disease Control and Prevention
Atlanta, GA

Derya Unutmaz, M.D.

Professor
The Jackson Laboratories
Farmington, CT

Sumeeta Varma, M.D., M.S.C.I.

New York, NY

Chris Wikman

Germantown, MD

Jarred Younger, Ph.D.

Professor
Department of Psychology
University of Alabama at Birmingham
Birmingham, AL

FAQs

What is the ME/CFS Research Roadmap Working Group of Council?

This working group was put in place to identify the research priorities for ME/CFS in order to move the field closer to clinical trials to develop treatments for the disease. The final report from the working group will be presented to the [NANDSC Council](#) for discussion and approval on May 15-16, 2024.

Is the ME/CFS Research Roadmap a scientific study?

The ME/CFS Research Roadmap is not a scientific study. The goal of the process to develop an ME/CFS Research Roadmap is to identify research priorities to move the field toward translational studies and clinical trials.

Who are the members of the working group?

The working group is composed of clinicians, researchers, leaders of ME/CFS non-profit advocacy and research organizations, and individuals with lived experience. The individuals with lived experience were identified through a self-nomination process.

How many people with lived experience are in the working group?

There are five individuals with lived experience in the working group of the NANDSC Council (see roster above). Also, there are an additional 21 people with lived experience participating in the roadmap process.

How do you define an individual with lived experience?

Lived experience refers to “representation and understanding of an individual’s human experiences, choices, and options and how those factors influence one’s perception of knowledge” based on one’s own life (Source: [HHS ASPE](#)). For this process, we define an individual with lived experience as a person living with ME/CFS, those with a family history of ME/CFS, caregivers/care partners, and/or patient advocates.

What is the goal of including people with lived experience in the ME/CFS Research Roadmap process?

The goal of including people with lived experience is to identify research priorities that are most appropriate and beneficial for those impacted by ME/CFS. These individuals will play an important role in the process by sharing their experiences, perspectives, and opinions, which will be incorporated into the final ME/CFS Research Roadmap.

What is the longest length of disease of participants with ME/CFS? How many individuals have full-time caregivers?

The illness duration ranges from 2 years to 25 years, with a majority being ill for 5-10 years. Most individuals chose to not share additional details about their disease.

How can researchers, clinicians, non-profit advocacy and research organizations, and others in the broader ME/CFS community get involved in the research roadmap?

We welcome input from the broader ME/CFS community, including from those with lived experience, on the draft research priorities. Visit our [IdeaScale campaigns](#) to learn about the research priorities for each topic area and provide comments (the deadline for comments was March 11, 2024). Information on other feedback opportunities will be posted on this page and shared via the [NIH ME/CFS listserv](#). [Subscribe to listserv updates](#). You can also provide comments at any time by sending an email to MECFSResearchRoadmap@ninds.nih.gov.

Webinar Series

Members of the working group and people with lived experience worked together to plan and execute eight webinars focused on specific topic areas in ME/CFS research. The goal was to assess current efforts and identify opportunities for research, and to develop draft research priorities for the roadmap based on discussions. Webinar topics included:

- Nervous system
- Immune system
- Metabolism
- Genomics/genetic susceptibilities
- Chronic infections
- Physiology
- Less studied pathologies
- Circulation



The webinars were open to the public and featured talks by experts in ME/CFS, including researchers and people with lived experience, and Q&A sessions.

ME/CFS Research Roadmap Webinar Series



Webinar videos and transcripts are available!

[Watch Webinars](#)

Webinar Planning Groups

Nervous System

Jarred Younger (Chair)
 Lisa Engel
 Craig Heller
 Lenny Jason
 Chloe Jones
 Laurie Jones
 Gudrun Lange
 Benjamin Natelson
 Lorraine Steefel

Immune System

Derya Unutmaz (Chair)
 Tracy Duvall
 David Kim
 Nancy Klimas

Roshan Kumar

Susan Levine

Alain Moreau

Angela Termini

Sumeeta Varma

Metabolism

Alain Moreau (Chair)

Tess Falor

Thomas Gierach

Ian Lipkin

Derek Simmonds

Derya Unutmaz

Chris Wikman

Genomics/Genetic Susceptibilities

Oved Amitay (Chair)

Miriam Boyer

James Holcomb

Tony Komaroff

Alain Moreau

Chris Ponting

Hayla Sluss

Linda Tannenbaum

Chronic Infections

Maureen Hanson (Chair)

Simon Carding

Kenneth Friedman

David Holcomb

Ikuko Kato

Nancy Klimas

Tony Komaroff

Katya Lavine

Beth Unger

Physiology

Craig Heller (Chair)

Maureen Hanson

Cindy Bateman

Nancy Harkness

Richard Simpson

David Systrom

Less Studied Pathologies

Beth Pollack (Chair)
Maureen Hanson
Cindy Bateman
Nancy Klimas
Michael Hermus
Cort Johnson

Circulation

David Systrom (Chair)
Cindy Bateman
Peter Cariani
Gwynn Dujardin
Benjamin Natelson
Beth Pollack
Elizabeth Weaver
Jarred Younger

Contact



[NINDS ME/CFS Research Roadmap](#)

Related Topics

- [NANDSC Working Group for ME/CFS Research](#)
- [Trans-NIH ME/CFS Working Group](#)
- [NIH Director's Blog on ME/CFS](#)
- [Report of the NANDSC Council Working Group for ME/CFS Research](#)  (pdf, 669 KB)

Last reviewed on December 02, 2024